THE CENTERED PROJECT: FINAL REPORT September 29th, 2003

September 29th, 2003 DJ Goodwin, MS, DrPH; Principal Investigator

BACKGROUND

In February 1998, President Bill Clinton announced the national initiative to eliminate racial and ethnic disparities in health by the Year 2010. The Department of Health and Human Services is supporting health disparities research to study factors that influence access to and quality of medical care; and, to stimulate community-based primary prevention and health promotion programs to reduce disparities in health.

Since 1999, the Centers for Disease Control and Prevention (CDC) initiated the Racial and Ethnic Approaches to Community Health (aka REACH) Program to fund community-based projects to implement creative interventions in communities of color in an attempt to reduce racial disparities in health. CDC recognized that traditional evaluation methods might not be appropriate for use in community settings.

In July 1999, the Council of State and Territorial Epidemiologists (CSTE) adopted a position statement committing CSTE to supporting state and national health disparity elimination efforts (available on the CSTE web site), and emphasized the need to concurrently address the socioeconomic factors that contribute to those disparities.

By the end of September, 1999, CDC awarded funding for an investigator-initiated Special Interest Project through the University of South Carolina's Prevention Research Center (USC-PRC) to South Carolina Department of Health and Environmental Control's (SC-DHEC) Bureau of Epidemiology (SIP#25PR, 1999; Grant Number U48/CCU409664 -- Total award: \$1,062,541). The purpose of the funding was to help develop the capacity of community-based organizations to evaluate interventions that are targeting elimination of racial and ethnic disparities in health. During Year-1 CDC also provided supplemental funding through the same grant to support the efforts of the Center for the Advancement of Community-based Public Health (CACBPH) to produce a community friendly "translation" of CDC's *Framework for Program Evaluation in Public Health*.

During Year-1, the name of the project was changed from SIP25PR to the CENTERED Project, as this acronym simplified the project name and incorporated the intent of the project. CENTERED stands for:

Community Evaluation Networks Targeting Elimination of Racial & Ethnic Disparities.

PROJECT GOALS

The three CENTERED project goals were:

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- 1. Creation of a highly diverse national Blue Ribbon Panel (BRP) of experts experienced in evaluating Community Based Public Health (CBPH) interventions to guide the project;
- 2. Development of a generic guide that could be used by community-based organizations (CBOs) to enhance their capacity to evaluate their health disparities elimination programs; and,
- 3. Establishment of a network of advisors who could support evaluation of CBPH programs targeting elimination of health disparities.

OUTCOMES

Goal #1: Creation of a highly diverse national advisory panel (the "national Blue Ribbon Panel" or "BRP")

The project's first goal was accomplished by selecting and convening a 25-member Blue Ribbon Panel of highly diverse advisors from across the nation who had expertise in the evaluation of community based programs. This was accomplished by dissemination of a call for applications from persons interested in serving as a project advisor and willing to commit to active participation for the duration of the project (3-years, with a possible extension to 6-years).

The call for applications was distributed broadly, including a posting on CDC's web site; notification of state health departments and schools of public health of the call; notification of the Center for the Advancement of Community Based Public Health in Durham, NC; notification of professional public health associations; and, other notifications of this opportunity.

During the 3-week search, seventy-eight applications were received. These were shared with an independent Blue Ribbon Panel (BRP) Selection Committee created by the project for sole purpose of screening the applicants to provide a short list of twenty-five candidates. The CDC Project Advisor (Bobby Milstein) and three of the five project investigators (Don Goodwin, Francisco Sy, and Deloris Williams) were present and participated in the BRP Selection Committee's deliberations, but did not vote in the final selection process. Their role was to monitor the process to assure that the list produced a highly diverse set of candidates in accordance with the vision of the PI and the expectations of CDC.

From the list of twenty-five candidates provided by the BRP Selection Committee, twenty were invited to become BRP members and to participate in the first project meeting (held in December 1999 in Charlotte, North Carolina). The PI had decided to hold vacant five seats on the BRP so the BRP members could select the remaining five members. This was to empower the newly formed BRP to actively participate in the project decision-making. Over the duration of the project, the BRP recommended the

appointment of six new members – the remaining five members, plus an additional member to replace an original BRP member who was unable to actively participate in the project meetings. The composition of the fully constituted twenty-five member national Blue Ribbon Panel is described in Table 1.

TABLE 1. Composition of the CENTERED National Blue Ribbon Panel (N=25)*.

Race/Ethn.	Acad	<u>Govt</u>	<u>CBO</u>	<u>Priv</u>	<u>Other</u>	Male_	<u>Female</u>	TO	<u> </u>
White African-Am Hispanic Native Am Asian/Pac Isl	3 2 2 1 2	0 3 1 0 0	0 5 1 1	0 2 0 0 0	0 1 0 0 0	2 6 1 0 1	3 0	3 13 4 2 3	12 52 16 8
TOTAL N: %:		4 16	8 32	2 8	1 4	10 40	15 60	25 	100

^{*}Members come from fifteen states & one territory: Arkansas, California, Hawaii, (native Hawaiian), Indiana, Michigan, New Mexico, N Carolina, Ohio, Georgia, Oklahoma, S Carolina, Texas, Virginia, Washington, Wisconsin, & Puerto Rico.

Goal #2: Development of a generic guide that could be used by community-based organizations (CBOs) to enhance their capacity to evaluate their health disparities elimination programs

In June-2000, the Center for the Advancement of Community Based Public Health (CACBPH), with advice and guidance provided by the CENTERED Project participants, completed the community friendly "translation" of CDC's *Framework for Program Evaluation in Public Health* (produced under CDC supplemental funding through USC-PRC). The final CACBPH product was called, *An Evaluation Framework for Community Health Programs*.

The <u>CENTERED Evaluation Guide</u> (submitted separately) is the project's output document that was designed to meet this goal. A second output, the <u>Pathways to Evaluation of Community-Based Programs</u> (submitted separately) was produced to accompany the <u>Guide</u> so users can appreciate the early work of the project and the invaluable guidance provided by the diversity of perspectives represented on the national Blue Ribbon Panel.

Goal #3: Establishment of a network of advisors who could support evaluation of Community Based Public Health (CBPH) programs targeting elimination of health disparities.

The list of project participants (investigators, Blue Ribbon Panel members, and ad hoc advisors and consultants) is provided at the back of <u>Pathways to Evaluation of Community-Based Programs</u>. The list provides contact information that will enable others to access individuals within this highly diverse network of CENTERED participants. It is hoped that this network serves as a useful resource for learning more about the project, its work, and evaluation of CBPH interventions. It should also be helpful for those trying to identify persons for technical advice and guidance as they begin using <u>The CENTERED Evaluation Guide</u>.

PROJECT MEETINGS & PARTNER EMPOWERMENT MECHANISMS

The recruitment, selection, and convening of the national Blue Ribbon Panel took place in a very short time period – the funding award to the University of South Carolina (USC) was in late September; the contract from USC to the South Carolina Department of Health and Environmental Control (SC-DHEC) took several weeks; and, the first meeting of the BRP was convened in early December, 1999. Following the first meeting, CDC's senior representative at the meeting sent the following note to the PI:

"I have just returned from the inaugural meeting of the national Blue Ribbon Panel (BRP) ... and wanted to express my personal appreciation, and that of my CDC colleagues, for the exemplary leadership and management you have demonstrated in making this critically important panel a reality.

"Operating on a time frame that many thought impossible, you ... (1) formulated and implemented a national recruitment plan for the BRP, (2) set up an objective review and selection process, and (3) completed the selection process. Simultaneously, you orchestrated the planning (including all logistical aspects) of the meeting. Then, you convened and managed the first meeting with great deference and respect to the participants. All ... in less than 3 months after receiving your cooperative agreement award. ...

"From any perspective, the effort to eliminate racial and ethnic health disparities constitutes a huge challenge ... one that will require great courage, innovation, and persistence. Thanks in no small part to you ..., the BRP is on sound footing and off to a good start. ..."

Marshall W. Kreuter, Ph.D, Director Prevention Research Centers Program Centers for Disease Control & Prevention Atlanta, GA 30333 [December 20, 1999] The project convened the Blue Ribbon Panel a total of nine times between its inception and the last meeting in April-2003. The meetings were held in variety of geo graphical locations around the United States (Charlotte, NC [twice]; Miami, FL; Albuquerque, NM; Atlanta, GA; San Antonio, TX; Seattle WA; Los Angeles, CA; and, Birmingham, AL) to enable participation by representatives of REACH and non-REACH community-based public health projects targeting elimination of racial/ethnic health disparities. While the project is based in South Carolina, no major meetings were held in South Carolina. This reflected a project policy adopted to respect the NAACP's boycott of South Carolina because of the concerns with the flying of the confederate flag on state capitol grounds.

To enhance the likelihood of active attendance at project meetings, those BRP members whose travel was not sponsored by their own agency/employer were provided a \$300 stipend for each meeting in addition to having most meals, transportation and lodging covered by the project. The BRP also participated in selection of the dates and locations of the project meetings, and in development of the meeting agendas. The members also selected three co-Chairpersons to serve as facilitators of the meetings and to represent the BRP during periods between meetings. The three co-Chairs consisted of two BRP members and the project PI.

Because of the diversity of areas of expertise and formal education (from one person with only part of an elementary school education, to another with two doctoral degrees), and wanting to demonstrate a valuing of the expertise brought to the project by community participants, name tags for project meetings listed only each participant's name, while omitting their formal degrees and affiliations. While some unhappiness was initially expressed by those most degreed/titled, in time even they freely expressed support for this decision. This simple act helped to make community participants feel more at ease and willing to join in the discussions.

Another purposeful decision to create an enabling environment for candid discussions to take place, was to use a single-layered horseshoe shaped seating pattern for the meetings. There was never a "head of the table", so every one was seated on the same level and in whatever seating pattern they felt most comfortable. Even when presentations were made during the meeting, no podium was used. Participants spoke from where they were seated and microphones were placed at each seat.

After the first project meeting, acting on a recommendation made by Dr. Kreuter (CDC), the proceedings for the plenary sessions of the remaining eight project meetings were captured by a contracted meeting transcriber. A written record of each meeting's proceedings has been retained for review by interested parties. While the plenary sessions were well documented, the many workgroup meetings were purposefully not transcribed in order to encourage free and open discussions of often controversial topics. However, after each workgroup session, the group would report their findings and recommendations to the plenary session at which time those summary reports were recorded and transcribed.

This system of documenting the work of the project proved to be very helpful as a resource from which to recover aspects of the discussions that might otherwise have been lost. Examples of the richness of the workgroup discussions is reflected in the <u>Pathways</u> document

OUTPUTS

One of the earliest recommendations of the BRP was that CDC modify its traditional operational time frames when working with CBPH interventions to enable what would constitute "fair trial periods" before assessing the success of a CBPH intervention. This recommendation originated out of the desire of the project's participants to support a very eloquent plea made by Rosamaria Murrillo (a REACH Project participant) during CDC's January 2000 REACH Evaluation Workshop. Ms. Murrillo made an appeal for CDC to consider the challenges to true community-based initiatives to work within the traditional CDC time frames when trying to compete for continuation funding. Her appeal was considered during a workgroup session during the second CENTERED project meeting. The BRP recommended that the support for Ms. Murrillo's appeal be conveyed with supporting rationale to CDC's Director. A letter was drafted through multiple iterations with BRP and investigator inputs until consensus was reached on the final wording. The process took several weeks, during which the tone became much less dramatic (see Appendix A). The process helped to establish credibility regarding empowerment of the BRP to influence project actions. While no formal response was received from the CDC Director, an informal response came in the form of a telephone rebuke from CDC to the USC's Prevention Research Center (Dennis Shepard). I sat in on that conversation and then traveled to CDC to discuss the issue. The point of concern was not the content of the letter as much as it was viewed as a potential violation of federal regulations regarding use of federal funds to advocate for federal funding of other programs. I was advised that had I written the same letter, but not from the project, then it would have been okay. From my perspective, the letter accomplished my intended goals: 1) It demonstrated my valuing of BRP inputs and recommendations; and, 2) It communicated to CDC the project's concerns regarding the lack of "fair trial periods" under CDC's routine operational time frames.

MEETINGS/CONFERENCES

During the life of the project, CENTERED participants will have disseminated the work of the project at the following meetings/conferences (authors and presentation titles are presented below):

- 1) South Carolina Minority Health Conference; Columbia, SC, January 2000.
- 2) South Carolina Annual Epidemiology Conference; Columbia, SC, March 2000.
- 3) CDC/NCCDPHP REACH Program's Evaluation Workshop; Atlanta, GA, 2000.
- 4) Council of State and Territorial Epidemiologists; New Orleans, July 2000.
- 5) American Public Health Association; Boston, November 2000.
- 6) CDC/NCCDPHP REACH Program's Evaluation Workshop; Atlanta, GA, 2001.

- 7) Association of State and Territorial Health Officers; 2000 Public Health Improvement Act ("Frist-Kennedy"), ASTHO Working Group; Wash, DC, 2001.
- 8) Council of State and Territorial Epidemiologists Portland, OR; Jun 2001.
- 9) 2nd National HIV Prevention Conference; Atlanta, GA; Aug 2001.
- 10) American Public Health Association; Atlanta, GA; Oct 2001.
- 11) American Evaluation Association; St. Louis, MO; Nov 2001.
- 12) Convocation of Southern States Epidemiologists; Charleston, SC; Dec 2001.
- 13) South Carolina Public Health Association; Myrtle Beach, SC; May 2002.
- 14) Council of State and Territorial Epidemiologists; Kansas City, MO; Jun 2002.
- 15) Convocation of Southern States Epidemiologists; Atlanta, GA; Dec 2002.
- 16) National Conference on the Relevance of Assessment and Culture in Evaluation (RACE) 2003; Tempe, AZ; Jan 2003.
- 17) South Carolina HIV Prevention Community Planning Leadership Summit; Columbia, SC; Jan 2003.
- 18) University of South Carolina, College of Nursing and Womens Research, Faculty Summer Research Camp; May 2003.
- 19) Council of State and Territorial Epidemiologists; Hartford, CT; Jun 2003.
- 20) American College of Epidemiology; Chicago, IL; Sept 2003.
- 21) National Dialogue on Cancer; Atlanta, GA; Sept 2003.
- 22) American Evaluation Association; Reno, NV; Nov 2003.

CENTERED PRESENTATIONS

- 1) Goodwin DJ. SC-DHEC Epidemiology Bureau's Support of Racial and Ethnic Health Disparities Elimination in South Carolina. Minority Health Conference; Columbia, SC, Jan 2000.
- 2) Goodwin DJ, Ruff G, and Heidari K. Racial and Ethnic Health Disparities in South Carolina (a panel presentation). South Carolina Annual Epidemiology Conference; Columbia, SC, Mar 2000.
- 3) Goodwin DJ. Evaluation Support for Community-Based Interventions That Target Elimination of Racial and Ethnic Health Disparities. CDC/NCCDPHP REACH Program's Evaluation Workshop; Atlanta, GA, Mar 2000.
- 4) Goodwin DJ. The Epidemiologist's Role in Eliminating Racial and Ethnic Health Disparities. Council of State and Territorial Epidemiologists; New Orleans, July 2000.
- 5) Goodwin DJ. Development of Networks for Supporting Evaluation of Community-Based Efforts to Eliminate Health Disparities. American Public Health Association; Boston, Nov 2000.
- 6) Easterling D. <u>Pathways to Evaluation: Progress Notes</u>, a refined version of <u>Pathways to Evaluation</u>. CDC/NCCDPHP REACH Program's Evaluation Workshop; Atlanta, GA, Feb 2001.
- 7) Goodwin DJ, Umilani-Tsark J, Zinzun M. CSTE Tribal Relations. Council of State and Territorial Epidemiologists [CSTE]; Portland, OR; Jun 2001.
- 8) Goodwin DJ. CSTE's Draft Epidemiology Capacity Assessment Instrument. First North American Congress for Epidemiology; Toronto, Canada; Jun 2001.

- 9) Goodwin DJ. Valuing Diversity in Developing New Approaches to Evaluation of Community HIV Prevention Interventions. 2nd National HIV Prevention Conference; Atlanta, GA; Aug 2001.
- 10) Goodwin DJ, and Zinzun M. Responding to Community Health Issues via Participatory Community-Based Health Partnerships. (A 90-minute panel session). American Public Health Association; Atlanta, GA; Oct 2001.
- 11) Conner RF, Reininger B, Brooks PE, Lowery C, Williams SM, and Goodwin DJ. Non-Traditional Approaches to Evaluation of Community-Based Public Health Interventions. (A 90-minute panel presentation). American Evaluation Association; St. Louis, MO; Nov 2001.
- 12) Goodwin DJ. Organizer and Chair of the following CENTERED sponsored sessions held during the Convocation of Southern States Epidemiologists, 2001; Charleston, SC; Dec 2001 the theme of the meeting was "Addressing Racial and Ethnic Disparities in Health":
 - May berry RM (Morehouse School of Medicine; and, a CENTERED BRP member), Brown CP (Florida A&M, Institute of Public Health; and, Member, Minority Affairs Committee, American College of Epidemiology). SES & Other Factors as Contributors to Racial & Ethnic Health Disparities (*Plenary*).
 - Jones-Saumty D (American Indian Research Group; University of Oklahoma Health Sciences Center; and, a CENTERED BRP member).
 Research in American Indian Communities: Issues of Methodology (*Plenary*).
 - McKeown R (University of South Carolina School of Public Health; and, Member, Ethics Committee, American College of Epidemiology). The 'Tuskegee Syphilis Study': Could the Same Thing Happen Today? (Breakout).
 - Do S. (President, Vietnamese American Medical Society). Primary Prevention of Hepatitis-B and Primary Hepatocellular Carcinoma Among Asian Americans Through HB-Immunizations (Breakout).
 - Conner RF (University of California-Irvine, School of Social Ecology, Department of Urban and Regional Planning; and, a CENTERED BRP member), Williams D (South Carolina Department of Health and Environmental Control; and, a CENTERED Investigator), and Coleman J (South Carolina Department of Health and Environmental Control; and, a CENTERED BRP member). The CENTERED Project's Non-Traditional Approach to Evaluation of CBPH Interventions (*Breakout*).
- 12) Goodwin DJ. Presentation of a Successful Long Term Community-Based Inner City Pest Control Intervention. South Carolina Public Health Association; Myrtle Beach, SC; May 2002.
- 13) Goodwin DJ. Session Organizer and Chair of the session titled: Racial & Ethnic Health Disparities Elimination: Confronting Health Disparities. Council of State and Territorial Epidemiologists; Kansas City, MO; Jun 2002. Session presentations:
 - Brown CP (Florida A&M, Institute of Public Health; and, Member, Minority Affairs Committee, American College of Epidemiology).

- Epidemiology and Minority Populations: A Review of the American College of Epidemiology's 1995 Statement of Principles.
- Butler AS (National Academy of Sciences, Institute of Medicine). Review of the 2002 IOM Report, "Unequal Treatment".
- Jones-Saumty D (American Indian Research Group; University of Oklahoma Health Sciences Center; and, a CENTERED BRP member). Research in American Indian Communities: Issues of Methodology.
- Jenkins T (South Carolina Department of Health and Environmental Control, Equal Employment Opportunities Director). Fair Employment Practices: Monitoring Methods & Policy Influence Mechanisms.
- 14) Goodwin DJ. <u>Chlamydia</u> Infections: Silent Contributors to Disparities in HIV and Infant Mortality Among African Americans and American Indians. Convocation of Southern States Epidemiologists; Atlanta, GA; Dec 2002.
- 15) Goodwin DJ. The CENTERED Evaluation Guidebook. National Conference on the Relevance of Assessment and Culture in Evaluation (RACE) 2003; Tempe, AZ; Jan 2003.
- 16) Goodwin DJ. Primary HIV Prevention: <u>Chlamydia trachomatis</u> and Health Disparities in HIV and Infant Mortality. South Carolina HIV Prevention Community Planning Leadership Summit; Columbia, SC; Jan 2003.
- 17) Goodwin DJ. Capacity Building Evaluation Support for Community-based Public Health Programs that Target Elimination of Racial and Ethnic Health Disparities. South Carolina HIV Prevention Community Planning Leadership Summit; Columbia, SC; Jan 2003.
- 18) Goodwin DJ. The CENTERED Project: Building Community Capacity to Evaluate Projects Targeting Elimination of Racial/Ethnic Disparities. University of South Carolina, College of Nursing and Womens Research, Faculty Summer Research Camp; May 2003.
- 19) Goodwin DJ. Racism, Racial Equity Indicators, and Participatory Approaches to Community Health. Council of State and Territorial Epidemiologists; Hartford, CT; June 2003. (Session title: "Social Determinants of Health: Context, Measurement and Interventions").
- 20) Goodwin DJ. <u>Chlamydia trachomatis</u> Infections and Correlations with Health Disparities in HIV Infection and Infant Mortality Rates (IMR) in South Carolina. American College of Epidemiology, Annual Meeting, Chicago, IL; Sept 2003.
- 21) Goodwin DJ. Evaluation of Community-Based Public Health Interventions: The <u>CENTERED Evaluation Guidebook</u>. American College of Epidemiology; Chicago, IL; Sept 2003.
- 22) Goodwin DJ. The CENTERED Project: An Overview. National Dialogue on Cancer. Atlanta, GA; Sept 2003.
- 23) Goodwin DJ. The CENTERED Project: <u>Pathways to Evaluation of Community-Based Programs</u> and <u>The CENTERED Evaluation Guide</u>. American Evaluation Association, Annual Meeting. Reno, NV; Nov 2003.
- 24) Goodwin DJ (Session Chair). Session title: Using Collaborative, Participatory and Empowerment Evaluation Techniques with Health Promotion Programs. American Evaluation Association, Annual Meeting. Reno, NV; Nov 2003.

- Bisset S, Cargo M, Delormier T, and Potvin L (all from the University of Montreal). Legitimizing Diabetes as a Community Health Issue: A Case Analysis of the Kahnawake School's Diabetes Prevention Project.
- Berezowski KM and Howard DCP (both from Howard Research and Instructional Systems, Inc). Putting Empowerment Evaluation Theory into Practice: Lessons Learned from a Youth Alcohol Harm Reduction Program.
- Bui UH, Brooks R, Mutchler MG, Chion MA (from the AIDS Project Los Angeles; and, the Center for HIV Identification, Prevention, and Treatment Services). Building Capacity to Evaluate HIV Prevention Programs Within Community-based Organizations.

OTHER PROJECT OUTPUTS

- 1) The CENTERED Project web site: www.scdhec.net/hs/epi/CENTERED -- the web site was established early in the project to enable the sharing of background information regarding the project, links to other web resources, and identification of the project participants (including their contact information). The site also includes a mechanism for users to provide their own inputs or ask questions and allows users access to the major project outputs and reports.
- 2) <u>An Evaluation Framework For Community Health Programs</u>. Produced in June 2000 by the Center for the Advancement of Community Based Public Health in Durhan, North Carolina through supplemental funds from CDC. This was a community-friendly translation of CDC's <u>Framework for Program Evaluation in Public Health</u> (<u>MMWR</u> Supplement No. 48; September 17, 1999; CDC Evaluation Working Group).
- 3) Letter to CDC Director regarding the need for "fair trial periods". (July 2000).
- 4) Pathways to Evaluation: Starting Points. (originially distributed at the 2000 REACH 2010 Evaluation Workshop; Atlanta, GA; revised in 2001 and again in 2003). This document was developed to provide a sense of the discussions that were occurring during the project meetings. Strong concerns were raised regarding the limitations of traditional evaluation methods as they often are neither appropriate nor relevant to the needs of community-based organizations serving racially and ethnically diverse communities. The title (Pathways) was chosen to convey the consensus opinion that rather than a generic immutable evaluation protocol (one size fits all) for use in evaluating community based programs, more helpful would be a generic framework that allows flexibility in the design, implementation, and analysis of evaluations dependent upon community interests and values. This ability to tailor CBPH program evaluations to "fit" community interests is a central theme that runs through the "CENTERED Evaluation Principles" and the CENTERED Evaluation Guide.

DISCUSSION

From the beginning of the project, the BRP felt strongly that the project's primary target output (the CENTERED Evaluation Guide) must include considerations of racism as both

a major factor contributing to health disparities, and as a significant constraint on the success of efforts to eliminate health disparities. This concern was reinforced during the course of the project when the Institute of Medicine published *Unequal Treatment* (2002) – CENTERED collaborated with Adrianne Smith Butler (one of the co-authors of this report) to share perspectives during the 2002 meeting of the Council of State and Territorial Epidemiologists (see above, CENTERED Presentation #13). Project participants felt strongly that unless racism is concurrently addressed as a potential contributing factor to health disparities, then whatever progress might be made towards health disparity elimination, would not be sustainable.

It was also clear that community members have relevant practices, knowledge and expertise that are often ignored, under valued, or not captured in traditional evaluation efforts. Therefore, evaluations needed to be participatory in nature to identify and work with the community's priority interests, in addition to those of the health program and the sponsor(s). Participatory evaluation processes are encouraged in the CENTERED Evaluation Principles to enable the community and program stakeholders to provide insights into the contextual issues that will enable a fair and accurate assessment of community needs and evaluation of programmatic successes.

Early in Year-2, CENTERED produced <u>Pathways to Evaluation: Progress Notes</u>, a refined version of the <u>Pathways to Evaluation</u>. This second draft was distributed to grantees of CDC's Racial and Ethnic Approaches to Community Health (REACH) Program during a CENTERED presentation at CDC's REACH Evaluation Workshop (Atlanta, GA; February 2001 – see above, CENTERED Presentation #6). Copies were also distributed to other community partners around the nation in a structured process to obtain additional feedback. The final Pathways document was produced in September 2003 to be disseminated as an accompaniment of the <u>CENTERED Evaluation Guide</u>.

During the 2001 Annual Conference of the American Evaluation Association (AEA), the CENTERED Project held a special session to enable project participants to share the CENTERED's <u>Pathways</u> concepts with a set of invited discussants. The following are extracts from the discussants feedback regarding the non-traditional CENTERED evaluation concepts.

• Kate Ababio Spring, Founder, African Evaluation Society

"I am very glad to see that [the CENTERED Project] makes a positive contribution in recognizing disparities in the locus of decision making... evaluation can help to improve the situation by first recognizing that it exists and then looking for ways to deal with it."

• Ricardo Millett, President, Woods Fund of Chicago.

"There is no doubt in my mind that the history and practice of program evaluation needs a healthy dose of diversity sensitivity we are attempting to infuse it with here today [because of CENTERED's work]. . ."

"Is there any such thing as 'objective truth' that evaluation logic can unveil with appropriately culturally sensitive methodologies? . . . Clearly, as an evaluation practitioner adhering in whole or part to the principles of the scientific model, anyone . . . in this room who thinks of him or herself as a practitioner of evaluation would have to answer affirmatively . . ."

"We assume that our tools and processes can lead us to making these kinds of connections. . . .but, perhaps we need to get at truth in some other way . . ." – [the CENTERED way]

• Melvin M. Mark, Professor of Psychology, Pennsylvania State University, Editor, American Journal of Evaluation.

"There is much wisdom and good sense in the [CENTERED] recommendations . . . for evaluators and I very much look forward to seeing the [CENTERED Project's "how to"] report for the full set of [CENTERED] recommendations."

• Mia Luluqueson, Evaluation Director, Partnerships for the Public's Health, California.

"... <u>Pathways to Evaluation</u>... resonated with me, including the importance of honoring the community's voice and capacity. In public health... there are very few opportunities where we really honor the community's capacities. Also, the underlying effort to understand the community's social, structural, historical and cultural influences and to look at how racism affects both program successes and the design and implementation of evaluations."

"[Evaluators], as human instruments, bring a set of tools, a set of skills, a set of experiences into the community within their 'community change making processes'. If this human instrument is powerful, and if it is effective and sensitive, then it can influence the evaluation and the program's ability to succeed."

"What I'd like to applaud is this group's [CENTERED Project] boldness and willingness to push on very difficult issues in evaluation; and, also, to take a look at some very hard issues, like racism. It's not an easy thing to do; there's a lot of feelings that come up and . . . a lot of resistance and I'm sure for the group it's been quite painful at times. So, I really applaud [CENTERED's] willingness to push forward regardless of how difficult it may have been."

• Michael Quinn Patton, Union Institute, Minneapolis, MN.

"There isn't a shot for poverty or community violence, there isn't an immunization that one can give for family violence and community conflict or for disparities around health. So the challenge to evaluation that the CENTERED Project

represents is the challenge of matching the evaluation approach to the nature of the problem and the nature of the situation."

"It's not that one ought never do a concrete immediate short-term very explicit project with predictable outcomes. Where we have a known explicit technology with a research base ... there are forms of evaluation that do that very well. The problem is, that in the public's ... and policy maker's mind, that's the only form of evaluation that is valued. That becomes the gold standard against which everything else is measured."

"['Health disparities elimination'] seems very vague, takes too long, it doesn't get to answers fast enough. As a community we have to be able to help articulate the challenge of our times, which is matching evaluation approaches to the [varying] natures of situations, the nature of problems, the complexity of outcomes, and the complexity of context. And that's very much what the CENTERED Project is doing. We need to be able to help those who consume evaluations and fund evaluations to understand both the complexity and importance [of such approaches] and to be willing to engage in these long term more complex . . . efforts."

"The challenge that UNICEF was hearing in Africa and that I hear from a lot of community based organizations is that [many] funders are only interested these days in 'immunization type' projects . . . that have immediate short term and concrete outcomes. There are fewer and fewer funders willing to do the long haul community change stuff, because they don't know how to evaluate it. . . . In a world of diverse and complex problems, we need the diverse and complex approaches represented by CENTERED's 'Pathways' . . . "

In 2001, CENTERED co-sponsored the annual meeting of the Convocation of Southern States Epidemiologists' (CSSE), which was held that year in Charleston, SC. The PI agreed to co-sponsor the meeting on the understanding that the theme of the meeting would be, "Addressing Racial and Ethnic Disparities in Health". The plenary sessions and several breakout sessions were sponsored by CENTERED and included presentations by a variety of project participants (see PRESENTATIONS below, [Goodwin DJ; Nov 2001] for the title and presenters of the sessions sponsored by CENTERED).

During the discussion period following the 2001 CSSE meeting's opening plenary session, the State Epidemiologist for one of the southeastern states stated to the audience that if he wanted to have staff that would be well trained and able to produce high quality work, he'd "hire someone that looks like himself" (white male). The principal plenary presenter (Dr. Robert Mayberry, Morehouse School of Medicine and CENTERED BRP Member) responded politely with a rationale for the need to train and employ more non-white epidemiologists (consistent with the 1995 recommendations of the American College of Epidemiology) in order to support the national initiative to eliminate racial and ethnic health disparities. The person simply repeated his statement, this time with emphasis, to which Dr. Mayberry respectfully responded, "Then, Sir, if you worked for me I'd have to fire you."

While the inflammatory nature of the State Epidemiologist's comment was disturbing, more disturbing was the absolute lack of any reaction to the statement from the audience. This exchange, coming during the opening plenary session of a three-day meeting to discuss the role of epidemiologists in the national initiative to eliminate racial/ethnic disparities in health, reinforced the importance of the project PI's efforts to use the forum to discuss health disparities. It provided an opportunity to disseminate the work of the CENTERED project and encourage support for positions taken by the American College of Epidemiology (Policy Statement: "Epidemiology and Minority Population: Statement of Principles", 05/1995: http://www.acepidemiology.org/policystmts/SoPrin.htm) and the Council of State and Territorial Epidemiologists (CSTE Position Statement 1999 EC-1: "Support of Federal and State-Based Efforts to Address Elimination of Health Disparities" available at the CSTE web site: http://www.cste.org/ps/1999/1999-ec-01.htm). The decision to cosponsor the CSSE meeting had been discussed with and was agreed to by the BRP and other CENTERED participants, and they were debriefed after the CSSE meeting.

The many presentations and discussions that took place during the project and addressed CENTERED's non-traditional evaluation strategies generally concluded with agreement that the CENTERED approach to CBPH evaluations represents an important positive enhancement to the field. These feedbacks were extremely valuable for reinforcing the concepts and encouraging our proceeding into such important (but "sensitive") areas as racism and consideration of racial equity indicators. It is hoped that the final CENTERED output – the <u>CENTERED Evaluation Guide</u>, will be helpful to community-based organizations, to the communities served by them, and to sponsors of CBPH programs. While the strategies may be non-traditional, we feel they present the best chance for achieving significant and sustainable gains in efforts to eliminate racial and ethnic disparities in health.

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APPENDIX A

EXERPTS FROM A LETTER TO CDC ABOUT "FAIR TRIAL PERIODS" WHEN WORKING WITH COMMUNITY-BASED PUBLIC HEALTH PROGRAMS

We believe that effective evaluation and programmatic success within community-based coalitions depends on reasonable expectations and authentic support on the part of funding agencies. Our concern is founded in our collective experience that one year is far too short a period for disenfranchised communities to be expected to come together and compete effectively for continuation funding.

It is felt that the one-year time frame unfairly penalizes new community-based collaborations that, if supported through a "fair trial" period, may prove to be effective at eliminating health disparities within their communities. Therefore, time frames, and other conventions of funders too, must change in order to support these new approaches and strategies toward solving longstanding complex health problems.

In our deliberations regarding community-based collaborations and the interventions with which they are associated, my colleagues have made their concern clear about sponsors abandoning support after having encouraged the mobilization of communities based upon promises and expectations of supports and change. This scenario has happened for decades, especially in communities of color, and becomes a fundamental challenge to getting such communities behind new community-based projects.

If CDC's goal for the REACH initiatives involves innovative, home-grown effective strategies to reduce racial disparities, it is even more clear that the one-year time horizon is an inadequate program strategy. It is our opinion that a "fair trial" period would consist of at least three years. In this regard, it is puzzling why CDC would decide not to continue funding many first-year REACH projects, but instead fund a second batch of previously unfunded REACH proposals for, yet again, only one-year.

Disadvantaged and underserved communities, especially those of color, already have a serious distrust of research, researchers and government agencies. This mistrust has deep historical roots for numerous reasons, including the infamous Tuskegee study. Far too often, researchers have approached and worked in communities to implement interventions and other types of research projects, then walked away from those communities when the "outside" researcher had extracted from the community what she/he wanted, often leaving behind nothing of real use to the community.

The REACH model is intended to be different. Researchers are supposed to be working with communities and building trust, capacity and interventions with greater potential for effectiveness from within the community. It is well documented that this model takes a significant amount of time. To pull funding and support from communities before they have had a fair amount of time to get going will only undermine the efforts, and will

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serve to reinforce the mistrust and frustration communities have with researchers and government agencies. To do so, is neither good community relationship building, nor good science. Research work in this area shows that these community processes require significantly more time.

Therefore, we recommend that CDC take purposeful steps to demonstrate its support for "fair trial" periods when mobilizing communities behind the national initiative to eliminate racial and ethnic health disparities. Demonstration of CDC's willingness to create a "fair trial" period could begin now by extending funding support for all of the Year-1 REACH projects. It could then be reinforced by similarly funding the second cohort of REACH projects. That this would cost more, is understood, but we strongly believe that the investment is necessary to ensure the success of this cutting edge initiative.

We recommend continuation funding be granted to all REACH 2010 Projects until a three-year "fair trial" period has passed. During this "fair trial" period, CDC should provide any needed technical assistance to support the 2010 projects.